PARENTS OF DEAF CHILDREN SEEKING INFORMATION AND SUPPORT ON THE INTERNET: THE AUSTRALIAN EXPERIENCE

by

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ABSTRACT

The introduction of newborn screening for hearing has refocussed attention on the information and support needs of families with deaf children. The Internet is providing an additional resource for families to access timely and relevant information and advice. However, the experiences and attributes of parents of deaf children who search the Internet for information and support remain largely anecdotal. This study aims to bridge some of this knowledge gap.

Parents of deaf children were recruited to complete two online surveys. The Parent Survey sought to establish the demographic details and Internet use patterns of parents who use the Internet to search for information about deafness. The online Support Group Survey asked parents about their experience of participating in online support groups.

One hundred and sixty-three respondents completed the Parent Survey. Analysis of the data found Internet use is unrelated to the age of the parent, the age of their child, where they live or their employment status. Their use of the Internet is also unrelated to the type of hearing loss of their child, if their child has a cochlear implant or an additional disability or medical condition, or the method of communication used by the child. Education level of the parent, however, does influence the level of Internet use. Qualitative data indicates the need for unbiased information that is evidence-based on a range of issues that are important for families to make informed decisions regarding raising a deaf child.

Twenty parents responded to the Online Support Group Survey. They participate in online support groups for the wealth of information and the support and understanding they receive from other parents. All respondents would recommend an online support group to other parents. The respondents indicated that the benefits significantly outweighed the limitations.

The two major issues this study has highlighted is the need for parents of deaf children to receive unbiased and evidence-based information from a variety of sources, including the Internet and online support groups, and the need to ensure that parents have access to timely and reliable information irrespective of education level, socio-economic status and ethnicity.

This study provides a foundation of knowledge for service providers and hearing professionals developing Internet resources for parents of deaf children in Australia.

Keywords: Internet, parents, hearing loss, patient education, self-help groups, social support.

STATEMENT OF ORIGINALITY

This dissertation is my original work and has not been submitted, in whole or in part, for a degree at this or any other university. Nor does it contain, to the best of my knowledge and belief, any material published or written by another person, except as acknowledged in the text.

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Signed:

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Thank you to the North Shore Deaf Children's Association Committee for pilotting the Parent Survey and a special thanks to the parents of Aussie Deaf Kids who continue to convince me of the potential of the Internet to provide parents of deaf children with the information and support they need.

On September 23, 1996, our youngest daughter lost most of her hearing at age 7. It began a remarkable journey for our family and has sent me in a direction that I would never have anticipated. This is for Bonny and my family – thanks for your patience and support.

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TERMINOLOGY

According to the Australian Association of the Deaf Guidelines:-

a. "Deaf (with a capitalized D) is used to describe those who use Australian Sign Language (Auslan) to communicate, and who identify as members of the signing Deaf community.
b. Deaf (with a small d) is a more general term used to describe the physical condition of not hearing, and also to describe people who are physically deaf but do not identify as members of the signing Deaf community.
c. Hearing-impaired is a term usually preferred by those who have acquired a hearing loss in late childhood or adulthood, or have a mild or moderate hearing loss. These people usually communicate using speech, lip-reading and residual hearing (often amplified by hearing aids).
d. Hard of hearing is sometimes used as an alternative term for "hearing-impaired" (*Guidelines for the Portrayal of Deaf People in the Media*, n.d.)."

For the purposes of this study, the term 'deaf child' shall include any child with a permanent hearing loss irrespective of the type (bilateral or unilateral), degree (mild to profound), management (hearing aids, cochlear implant or neither) or mode of communication (oral, manual or both). Terms such as 'hearing impaired', 'hard of hearing', 'Deaf' and 'deaf' will all be classified as 'deaf' in this study.

Chapter 1

INTRODUCTION

Newborn screening for hearing has gathered considerable pace over recent years, as research indicates improved speech and language outcomes for babies diagnosed and receiving appropriate intervention by six months of age (Arehart, Yoshinaga-Itano, Thomson, Gabbard, & Brown, 1998). However, over ninety percent of children with a hearing loss are born to hearing parents who use spoken language to communicate (Luckner & Velaski, 2004). As a result, these parents have little understanding of hearing loss in children or its management. Shortly after diagnosis of their infant's hearing loss, parents are required to evaluate information and outcomes regarding issues such as technology for hearing impairment, communication options, education and habilitation (DesGeorges, 2003; Kurtzer-White & Luterman, 2003).

Studies show that parents of children with a disability or other special health care needs are turning to the Internet for both information and support. A common concern and frequent frustration for families with a child with a disability, is their difficulty finding timely and relevant information. Increasingly they are turning to the Internet to find the information and support they require. The experience of Australian families searching for information and support on the Internet, however, remains largely unexplored.

1.1 HEARING LOSS IN AUSTRALIAN CHILDREN – THE STATE OF PLAY IN 2005

The strides made in the development of technology which has seen the roll out of the Internet into homes across the country, has also changed the detection and management of hearing loss in children.

The prevalence of hearing loss in children varies according to the level and type of hearing loss considered. In Australia, the incidence of children with a permanent hearing loss of 40dB or more in the better ear is approximately 10 to 15/10 000 live births. This equates to approximately 250 to 400 births in Australia each year and indicates that hearing impairment at levels which can cause severe speech and language difficulties, is relatively common (Birtles et al., 1998). Hearing impairment in children not only affects their ability to acquire language but may have detrimental effects on their cognitive and socio-emotional development, resulting in educational difficulties and the sequelae of this underachievement into adult life (Birtles et al., 1998).

1.1.1 Newborn hearing screening

By the mid 1990s, there was a growing body of international research which found that "babies whose permanent bilateral hearing impairment is diagnosed before the age of six months, and who receive appropriate and consistent early intervention, have significantly better language levels than those children identified after the age of six months." (*Australian Consensus Statement on Universal Neonatal Hearing Screening*, 2001)

Techniques for effectively screening for hearing impairment in newborns were also being refined. Otoacoustic Emissions (OAE), Auditory Brainstem Response (ABR)

audiometry and Automated Auditory Brainstem Response (AABR) audiometry were all quick to administer and cost effective. More importantly, they demonstrated sensitivity estimates of 80 percent or higher and specificity above 90 percent (Birtles et al., 1998). Studies also showed the AABR could achieve false-positive rates as low as 2 percent. This meant that the technology was available to "enable effective screening of hearing impairment in newborns during natural sleep or quiet rest." (*Australian Consensus Statement on Universal Neonatal Hearing Screening*, 2001)

Several hospitals around Australia began screening infants considered at high risk of hearing impairment such as infants who had required neonatal intensive care. This strategy, however, meant that there were still a significant number of babies with no risk factors, who were not being diagnosed with a hearing impairment at an age known to be optimal for speech and language acquisition (*Australian Consensus Statement on Universal Neonatal Hearing Screening*, 2001).

In November 2001, the Australian National Hearing Screening Committee issued an Australian Consensus Statement on Universal Neonatal Hearing Screening recommending that a "program of universal neonatal hearing screening should be introduced across all states and territories in Australia in order to detect children with hearing loss at the earliest possible age." New South Wales was the first state to introduce a universal screening for hearing program in December 2002, known as Statewide Infant Screening for Hearing (SWISH), and the other states are progressively following suit.

Parents whose babies are diagnosed in an infant screening program are required to make some difficult choices about the management of their baby's hearing loss at a time when they are emotionally vulnerable. Mothers are recovering from the birth, and parents and siblings are adjusting to new family dynamics and roles. The choices are "formidable and life altering" (Kurtzer-White & Luterman, 2003) and are not made easier by the array and levels of service provision and sources of information within Australia.

1.1.2 Funding and service provision within Australia

The funding and provision of services for children with a hearing loss is diverse. Children diagnosed with a permanent hearing loss receive all audiological services through Australian Hearing which is funded by the Australian Government through the Department of Human Services. Australian Hearing provides audiological assessments, hearing aids and other assistive technologies to all children aged 0 to 21 years of age through their Community Service Obligation. Australian Hearing has approximately 15 000 paediatric clients. Ninety percent of these are fitted with hearing aids and approximately 10 percent have cochlear implants. In the year ending 31 March 2004, Australian Hearing provided 1 295 children under 17 years of age with a hearing aid for the first time (*Number and percentages of deaf children in Australia*, 2004).

Screening for hearing is the responsibility of the State Governments. Early intervention services and school education are provided by either the State Department of Education, the Catholic Education Department in each State or privately and publicly funded service providers who also supply itinerant teacher

support to children attending Independent schools. Cochlear implants may be funded by the Australian Government or private health funds.

1.1.3 Information needs of parents

Each service provider supplies parents with information. The initial source of written information is "Choices" – which is provided free-of-charge by Australian Hearing to the parents of a child with a hearing loss. Parents also receive information from health professionals and educators, a number with their own particular opinions and biases, particularly in institutions which have methodology-driven programs (Li, Bain, & Steinberg, 2003; Luterman, Kurtzer-White, & Seewald, 1999). There is, however, a growing call by parents to provide them with the unbiased information and support they need in order to make well-informed decisions about the management of their child's hearing loss (DesGeorges, 2003).

The decisions parents need to make are numerous.

1. Hearing aids and cochlear implants

   Infants diagnosed with a permanent hearing loss are generally fitted with hearing aids. Children with a severe to profound sensorineural hearing loss who receive little or no benefit from their hearing aids, are offered the option of receiving a cochlear implant (*Choices*, 2005). Cochlear implants are, however, viewed with deep concern by the Deaf Community. Their views are significantly at odds with the cochlear implant programs (*Policy on Cochlear Implants,* n.d.).

2. Communication choices

One of the principle benefits of early identification of hearing impairment is that appropriate access to language and communication can be introduced in the critical period for language development (Birtles et al., 1998). Age-appropriate language is pivotal to the cognitive, social and emotional development of the deaf child. The best method of providing this appropriate access to language remains a controversial issue amongst educators, parents and the Deaf community today. Luterman et al (1999) note, "The history of education of the deaf is replete with methodology wars; the loser in these monumental battles has been the deaf child."

Broadly speaking, the choices are:-

- Oral communication encourages the child to use their residual hearing and develop spoken language.
- Manual communication - the child's first language is Australian Sign Language (Auslan) which is a "linguistically complex and sophisticated language with its own grammar and lexicon" (*Auslan - Australian Sign Language*, 2003)
- A combination of oral and manual communication which can take a number of forms, the principal ones being:-
    - A bilingual approach has Auslan as the first language and English as the child's second language.

- Total communication is the simultaneous use of the spoken word and signs used to match that word. These signs may be different to the Auslan signs and referred to as Signed English. This approach is generally not one supported by the Deaf Community.

3. Early Intervention and School Education

   Choices for early intervention and school education are dependent on the method of communication the family chooses to adopt. Children may attend schools with a hearing unit or be integrated into mainstream settings with support from an itinerant teacher of the deaf. Educational resources that meet the particular communication needs of each child, however, are not always available at settings convenient for the family.

The introduction of newborn screening for hearing has also highlighted the number of children born with a unilateral hearing loss. While these children have been shown to have an increased risk of failing a year at school (McKay, 2002), they are not eligible for funding for assistance within our school systems and their audiological and educational management remains ad hoc. These families have access to minimal information and the best audiological method for management of these babies is inconclusive.

While traditionally, parents have sought information from professionals and other families with deaf children, they are also now turning to the Internet to provide them with unbiased information and support.

1.2 THE INTERNET AND THE WORLD WIDE WEB

The development of the Internet and World Wide Web over the past decade has provided us with unprecedented access to information. Every person able to access the Internet can now read information that was previously largely the domain of students and academics. The dream behind the World Wide Web, according to its developer Tim Berners-Lee, was to create a common information space where we can "communicate by sharing information" (Berners-Lee, n.d.). Health consumers have been enthusiastic adopters of Internet technology and the ways in which consumers access the vast wealth of information on the World Wide Web and the accuracy and reliability of that information has now become the focus for the healthcare industry.

The term "Internet" officially came into existence on October 24, 1995 when The Federal Networking Council (FNC) unanimously passed a resolution to define this global information infrastructure and call it the "Internet". The Internet comprises the computers and cables and the networks that connect them to each other. A variety of different programs including email, the World Wide Web and video and audio channels now use the Internet to encode information and deliver it in a user-friendly format to consumers around the world (Berners-Lee, n.d.).

1.2.1 The Australian experience

In 1987-88, the Carrs Report proposed that the Australian Vice-Chancellors' Committee (AVCC) provide funding for the establishment of a network for the transmission of data and other electronic services such as facsimiles. This network was named AARNet (Australia's Academic and Research Network) (Clarke, 2004).

It was the transfer of the commercial infrastructure of AARNet to Telstra in July 1995 which facilitated the use of the Internet by households throughout Australia.

Today Australians are amongst the highest users of the Internet in the world and the number of homes connected to the Internet continues to grow rapidly. Fifty-three percent of Australian households had Internet access in 2003 (*Household Use of Information Technology, Australia*, 2004). Households with children under 18 are the biggest users of the Internet with 48 percent having access to the Internet at home in 2000 (*Save@Home*, 2004).

Since the deployment of high-speed connections via broadband services in 1997, there has also been a steady rise in its take-up with a 121.8 percent increase in the year prior to March 31, 2005 (*Snapshot of broadband deployment as at 31 March 2005*, 2005). According to the Australian Bureau of Statistics, almost one million households had broadband access in September 2004. The 'always on' nature of broadband connections changes the way consumers use the Internet by expanding their online activities and increasing their frequency of use (Horrigan & Rainie, 2002). Broadband users also tend to search many sources for the information they want and find any regulation which may preclude them from information to be an anathema - the open content of the Internet is what is appealing to them (Horrigan & Rainie, 2002). "[Broadband] technologies can transform the way people live, work and do business." (*Australia's Broadband Connectivity: The Broadband Advisory Group's Report to Government*, 2003)

A number of factors are known to influence a consumer's use of the Internet:-

- *Age*

  Children and young adults are the greatest users with about 80 percent of 18 to 24 year olds using the Internet. Australians aged 55-64 are showing the fastest growth in take-up of Internet access (*Save@Home*, 2004).

- *Household income*

  High income households are bigger Internet users. Retirees and the unemployed are the most disadvantaged groups in terms of Internet connections at home (*Save@Home*, 2004).

- *Access speed*

  While almost all Australians can access the Internet via a telephone line, the speed of access tends to be slower in rural and remote areas (Curtin, 2001).

- *Education level*

  Consumers with a university degree are two and a half times more likely to have access to the Internet (Curtin, 2001).

- *Indigenous versus non-Indigenous background*

  The 2001 Census showed that 16 percent of the Indigenous population used the Internet with 9 percent accessing it at home. Comparison between the Indigenous and non-Indigenous population is, however, problematic with differences in age distribution between the two populations. However, the differences in Internet use across the various geographic areas, is worth noting. The non-Indigenous population generally maintains a high use of Internet use irrespective of geographic area. The difference in Internet use between Indigenous Australians in major cities and very remote areas is marked, with 25 percent of city dwellers compared to 4 percent in very remote locations using

the Internet. Only 1 percent of the Indigenous population used the Internet from home in a very remote location compared to 23 percent of the non-Indigenous population (*Use of information technology by Aboriginal and Torres Strait Islander peoples*, 2004).

- *Marital status*

  Fewer single parents use the Internet than married parents. Single parents use the Internet largely for communication while married parents are more research-oriented in their use (Allen & Rainie, 2002).

- *Gender*

  Mothers are more likely to search for health information than fathers (Allen & Rainie, 2002).

- *Ethnicity*

  Ethnic minorities are an under-investigated group in terms of their Internet use. The availability of multi-language web sites in Australia is limited which makes Internet access difficult for people from a non-English speaking background (Curtin, 2001).

- *Cost*

Cost of access is the major reason why households with computers are not connected to the Internet (Curtin, 2001).

Chapter 2

LITERATURE REVIEW

A literature search was carried out of health, education, psychology and sociology journals using a number of databases including Medline, PsychInfo, CINAHL and ERIC. Articles published prior to 1995 and articles in languages other than English were excluded. The search included terms for parents, hearing loss, patient education, patient information, Internet and support groups (Table 1). References mentioned in articles and not found in the search were accessed and included when appropriate.

Table 1. Key search words and MeSH category

Key word	MeSH category
Parents	Parents
Deaf	Hearing loss
	Hearing Impaired Persons
Internet	Internet
Information	Patient education
Email	Electronic mail
Support group	Self-help groups
	Social support

Articles were included or excluded after a reading of the abstracts. The paucity of available research on the Internet use of parents of deaf children meant that articles found which reviewed parents use of the Internet for information about their

child's health or for support to deal with a child's medical condition or disability were included.

2.1 THE INTERNET IN HEALTHCARE

Information technology will have "a tremendous impact on the future of healthcare delivery and practice" (Young, 2000). Email between patient and healthcare provider, electronic health records and sophisticated telemedicine systems can deliver state-of-the-art healthcare to remote and underserved populations or the disabled, chronically ill and elderly in their homes. "Online technologies offer the health and education sectors opportunities to expand their reach, deepen their quality and usefulness, and improve the efficiency of their delivery" (Swanson, 1999).

The Internet has provided us with more readily available health information than any time in history and it is possible to find the answer to most health queries whenever they arise. The control of health information has moved away from the expert towards the consumer (Smith, 2001; Yellowlees & Brooks, 1999) and has allowed consumers to make informed decisions regarding their health care. The Internet has escalated the trend of patients wishing to be active participants in their healthcare and well-being (Eng et al., 1998; Peterson, 2000; Young, 2000).

The Internet is changing the delivery of healthcare to remote and underserved communities through simple or sophisticated telemedicine applications. Telemedicine can improve the quality of healthcare for consumers by providing

timely consultations with specialists while reducing the time and cost of travel for consumers (Young, 2000).

The use of telemedicine for children with special needs has been investigated. Children with special needs require teamwork and a close network of professionals caring for them and telecommunications can be an important link in this network (Robinson, Seale, Tiernan, & Berg, 2003). In Australia, telemedicine has been demonstrated to be an effective method of providing healthcare to children with certain health needs and children living in rural or underserved communities (Crowe, Hailey, & de Silva, 1996; Gelber, 2001; Gelber & Alexander, 1999; Hawthornthwaite, 2002).

In the US, evaluation of telemedicine programs providing services to children with special healthcare needs, has demonstrated a high level of satisfaction with the service amongst patients, their families and the service providers. These programs have generally provided ongoing evaluation and rehabilitation to special needs children following hospitalisation (Karp et al., 2000; Robinson et al., 2003). In these studies, the telemedicine clinics helped forge stronger relationships between the various personnel working with the family although in one study, communication and information sharing between the local primary care doctor and the tertiary centre did not increase as had been anticipated (Robinson et al., 2003). The continuity of care and the education of local service providers using the telemedicine service have been shown to enhance the ability of local services to meet the needs of the child and their family in their local community (Farmer & Muhlenbruck, 2001).

In the area of deafness, telemedicine remains largely unexplored. A pilot study has demonstrated that the remote assessment of hearing can be accomplished via an Internet Protocol (IP) network (Givens et al., 2003). Otolaryngologists in Western Australia have conducted a small study of the potential for remote consultations using various tele-otoscopy systems. Future studies will investigate whether "high-quality video-otoscope images, together with audiometry and tympanometry data and a clinical history, will allow an ear specialist to make a confident assessment and provide advice to the remote healthcare worker and the patient"(Eikelboom, Atlas, Mbao, & Gallop, 2002) Videoconferencing is being used by some of the early intervention services in Australia to support children and families in remote locations although evaluation of these models is not documented in the literature.

Medical consultations are becoming shorter and lengthy discussions with the healthcare provider are often not possible (*Networking Health: Prescriptions for the Internet*, 2000). Health consumers are turning to other ways of meeting their health information needs. Email communication between consumer and healthcare provider is a growing area of interest. Studies which have examined the issue of physician-patient email have found almost half of the parents surveyed would like to communicate with their doctor via email (Baraff, Wall, Lee, & Guzy, 2003; Semere et al., 2003). Fifteen percent of parents at one clinic had used email to communicate with their doctor in the previous year (Baraff et al., 2003). The asynchronous nature of email provides busy doctors and consumers with an effective and convenient method of communicating between appointments

although issues of confidentiality, integrity of the data and the timeliness of replies still need to be addressed (*Networking Health: Prescriptions for the Internet*, 2000).

The ubiquity of the Internet has facilitated the development of electronic health records. Consumers have the potential to access their health records at any location where the Internet is available. The Australian Government has recognized the potential of the Internet to better manage clinical information of consumers throughout the country. The National Health Information Standards Plan for Australia aims to develop a "national framework for the use of electronic health records for service-delivery purposes to provide a means of improving the efficiency, safety and quality of health care" (*Setting the standards: a national health information standards plan for Australia*, 2001).

While telemedicine, email communication and electronic health records hold promise for the assessment and ongoing treatment of consumers, an ongoing trend in healthcare is toward the informed consumer. This trend heightens "the need for consumers to have access to reliable health information and open channels of communication to care providers and other health professionals" (*Networking Health: Prescriptions for the Internet*, 2000). The Internet has the potential to improve consumers' knowledge about health and disease prevention. It can assist consumers to effectively navigate through the healthcare system and facilitates access to information and support through web sites and online consumer self-help groups (*Australia's Broadband Connectivity: The Broadband Advisory Group's Report to Government*, 2003; Eng et al., 1998).

2.1.1 Health information on the Internet

Healthcare providers and consumers alike have recognized the value of the Internet to provide health information to large numbers of consumers. Increasing numbers of web sites are devoted to the diagnosis and management of diseases and disabilities or promoting various healthy lifestyle choices. Consumers are visiting their doctors with computer printouts of information they have found on the Internet (Pemberton & Goldblatt, 1998), and many health professionals have been ill-prepared for this change in the professional-patient dynamic (Jadad, 1999). In addition, a large population of patients are now turning to the Internet for a second opinion on the advice they have received from their health professional (Ferguson, 1999).

The Australian Government, in the National Health Information Standards Plan for Australia, has recognised the importance of providing access to information technology to all Australians at sufficient bandwidth and affordable cost (*Australia's Broadband Connectivity: The Broadband Advisory Group's Report to Government*, 2003). It has been argued, however, that while the intentions of the Australian Government are good, considerable work needs to be done on policies and implementation (Swanson, 1999).

The evidence of Australians' use of the Internet for healthcare information is sparse. A South Australian study found the prevalence of online health seekers to be 21 percent. The authors indicate that the Australia-wide prevalence is likely to be slightly higher, as Internet use in South Australia is lower than in the general Australian population (Bessell, Silagy, Anderson, Hiller, & Sansom, 2002).

The quality of health information on the Internet remains an area of concern for academics and health professionals. Unreliable or outdated health information is not only found on the Internet (Noll, Spitz, & Pierro, 2001) but the ease of access and the democratic nature of the Internet, make it particularly vulnerable. While consumers have access to peer-reviewed journals (such as Medline and PsychInfo) and several healthcare providers offer gateway services which include information that meets certain quality criteria (Shepperd, Charnock, & Gann, 1999) (such as the Commonwealth Government's Health*Insite*), the reality is that consumers use generic Internet search engines to find the information they require. The 8th HON Survey of Health and Medical Internet Users showed that 46 percent of patients and 28 percent of health professionals preferred general search engines (*Excerpt of the 8th HON's survey of health and medical internet users*, 2002).

Several organisations have developed rating systems to assist consumers to identify valid health information on the Internet although the validity of many remains questionable (Gagliardi & Jadad, 2002). The need for accreditation of health web sites divides opinion. Consumers fail to verify seals of approval or may simply be unaware of their existence (*Excerpt of the 8th HON's survey of health and medical internet users*, 2002) and, furthermore, parents are less likely to check the source of the information than non-parents (Allen & Rainie, 2002). Besides, it is unclear whether consumer use of rating instruments has any impact on their health outcomes (Gagliardi & Jadad, 2002).

While the information needs to be accurate and current, it must also be in a form that consumers are able to understand. Adults of all reading abilities prefer easy-

to-read information (D'Alessandro & Dosa, 2001). Studies looking at the readability of health information available to consumers have found that it is not written at a level considered appropriate for the majority of consumers (D'Alessandro & Dosa, 2001; Graber, Roller, & Kaeble, 1999). Criticism of readability tests, however, includes that prior experience and motivation are not taken into consideration. Consumers with chronic diseases and disabilities may be able to read more complex information as they become familiar with the disability and its terminology and jargon (McCray, 2005; Shepperd et al., 1999). Furthermore, eighty percent of patients who access web sites for health professionals do so to obtain more complex information (*Excerpt of the 8th HON's survey of health and medical internet users*, 2002).

The Australian Government Information Management Office does not specify a singular rule for reading levels for consumer publications but does promote the value of Plain English and inclusive communication (*Style manual for authors, editors and printers*, 2002).

2.1.2 Online health information and child health

The quality of information available to parents about child health issues has been investigated in a few studies mainly looking at paediatric surgery and pain management in children. A review of paediatric oncology on the Internet, highlighted the difficulty in locating information pertaining to specific childhood cancers (Cotterill, 2001). Another study which used six search engines to assess 300 search engine listings using the keywords 'ambiguous genitalia' and synonyms found only 5 (1.6%) of the accessible pages offered information that conformed to

standard paediatric surgical recommendation for treatment (Corpron & Lelli, 2001).

The accuracy of online health information in other studies has been less concerning with more than three-quarters of the reviewed sites providing accurate information for parents (Chen, Minkes, & Langer, 2000; Oermann, Lowery, & Thornley, 2003). An evaluation of 40 web sites on the management of pain in children found 29 (72.5%) provided information that was useful for parents to make informed decisions about treatment of their child's pain. However, only nine of the sites met all the Health Information Technology Institute (HITI) criteria for assessing health information on the Internet and had reading levels appropriate for most parents (Oermann et al., 2003).

Although the need for accurate and current information is recognised in healthcare facilities, a study of 141 web sites dealing with diaphragmatic hernia (CDH), abdominal wall defects (AWD), paediatric inguinal hernia (IH) and pectus excavatum (PE) found that less than a quarter of these web sites referred users to other reliable sources of information (Chen et al., 2000).

The role of the health professionals as the information gatekeeper is changing and health professionals need to play a proactive role in assisting and guiding patients to suitable online resources (Cotterill, 2001).

2.2 PARENTS AND THE INTERNET

In 2002, the Pew Internet and American Life Project published a report specifically looking at how parents in the United States use the Internet. There has been no comparable study carried out in Australia. The US study found that parents with a child living at home are considerably more likely to use the Internet than non-parents (Allen & Rainie, 2002). Online parents, however, use the Internet less frequently and for shorter periods of time than non-parents.

Parents are fervent online health seekers with 67 percent reporting using the Internet to search for health information. Parents visit more sites when they conduct a health-related search and they tend to talk to their doctor about the information they find online. They are, however, not as rigorous in checking the potential accuracy and reliability of the information they find. Married mothers are the biggest health information seekers and single fathers are the least likely to search for online health information. A significant number of parents who participate in online groups report they mostly lurk in those groups- they read but tend not to post messages (Allen & Rainie, 2002).

2.2.1 Parents seeking health information

A number of studies have been done looking at the Internet use of parents visiting various paediatric hospital clinics – dermatology (Lai & Mallory, 2000), ophthalmology (Rahi, Manaras, & Barr, 2003), renal (Cargill & Watson, 2002), surgery (Noll et al., 2001) and paediatric outpatients (Tuffrey & Finlay, 2002). Approximately twenty percent of parents visiting these clinics had used the Internet for additional information.

Noll et al. (2001) found similar percentages of parents using the Internet in a cross-sectional prospective study of parents of 108 children admitted to a children's hospital for surgery. Twenty-four percent of the parents had used the Internet for additional information and 77% of these reporting they were satisfied with the information they found. Interestingly, only 54% of the parents were satisfied with the additional information they received from their general practitioner. Despite this, the study found no difference in the knowledge of the child's condition between parents who sought additional information from their general practitioner and those who had obtained information from the Internet, books or magazines.

A cross-sectional study of families with children requiring cardiac surgery for congenital heart disease found 58% used the Internet to obtain additional information about their child's cardiac condition. Ninety-five percent of those accessing the Internet reported finding the information helpful or very helpful in improving their understanding of their child's condition (Ikemba et al., 2002).

The potential power of the Internet has been reported in a study that examined the effect of the Internet on parent decision-making in the treatment of congenital idiopathic clubfoot. A dramatic change in referral patterns to the authors' clinic was evidenced after information on a particular treatment for clubfoot was placed on the Virtual Hospital of the University of Iowa web site. Patients seen at the clinic by one author rose from 6 in 1998 to about 60 in 2001, with 75% of these being self-referrals (Morcuende, Egbert, & Ponseti, 2003).

Possibly more relevant to parents of deaf children is a study of parents visiting two general genetics clinics in an urban and rural setting in the US. Forty-seven percent of these parents had searched the Internet for genetics-related information before visiting the clinic. While 46% of the respondents had searched the Internet for information in layman's terms, 41% found the information difficult to understand or confusing. Three-quarters of the parents who had used the Internet for genetics-related information found it a positive experience (Taylor, Alman, & Manchester, 2001).

A study of 90 parents of babies admitted to a neonatal intensive care unit found 44% of the parents searched the Internet for information about their baby's condition. Interestingly, this group of parents searched the Internet less often after the birth of the baby when one would expect their need for information to be greater. The authors speculated that the crisis situation surrounding the birth of the baby, lack of time and the amount of reading material provided by the NICU may be the reason for this downturn in Internet use (Dhillon, Albersheim, Alsaad, Pargass, & Zupancic, 2003). This finding could have implications for parents of newly diagnosed babies with a hearing loss and their access to Internet resources.

The Internet experiences of 788 parents of disabled children on a range of carers databases in the UK found that 72% of those who used the Internet searched for information directly related to their parenting of a disabled child including medical information, benefits and services. A third of this group used the Internet to contact organisations relevant to their child's disability. Ninety percent of the Internet users had computers at home and also used the Internet for a range of

activities that allowed them to maintain a reasonable quality of life. Activities such as shopping online, keeping in touch with family and friends and leisure pursuits helped to provide some balance in their lives in situations which can be socially isolating and difficult (Blackburn & Read, 2005).

The demographics of the families in these studies are fairly constant – over ninety percent of respondents are female. Internet users tend to be better educated, more affluent and with a mean age of around 35 years. More than fifty percent access the Internet from home. The issue of the "digital-divide" is a common concern and Blackburn and Read (2005) suggest that this may be an area that needs to be considered by governments. Barriers to computer and Internet use for families with disabled children need to be removed or reduced to overcome some of the traditional difficulties of raising a disabled child such as reduced employment opportunities and social isolation.

2.2.2 Online support groups

The Internet has also provided the health consumer with the opportunity to access information and support through online support groups. Online support groups bring together individuals with a common problem or experience in order for them to share information and support. Online support groups are not only informative but can be very specific and allow participants to be flexible about where and when they access the group (Potts, 2005). Health-related groups are one of the fastest growing areas for online support groups (Gary & Remolino, 2000). Traditionally, groups have been shown to be an effective way of providing information, education and support (Galinsky, Schopler, & Abell, 1997). While

social support is a predictor of the well-being of families with disabled children, access to traditional support groups is not always possible. Online support groups are an attractive alternative to face-to-face groups, providing support and information at a place and time that is convenient to the parents. Geographical boundaries and social barriers are removed and many of the difficulties parents encounter attending face-to-face groups are absent (Gary & Remolino, 2000; White & Dorman, 2001).

The limitations of online groups have come under scrutiny. The literature cites the quality of information and the potential for misinformation or misinterpretation as a concern, particularly in groups run by consumers (White & Dorman, 2001). While the evidence suggests that misinformation is often corrected by participants, it may not be done in a timely manner (Han & Belcher, 2001; White & Dorman, 2001). Consumers cite different concerns such as confidentiality, different stages of group development and lack of feedback as some of the frustrations (Gary & Remolino, 2000).

There is a growing volume of literature reviewing the efficacy of Internet support groups and their use in a number of health areas such as breast cancer and depression. Internet support groups for parents have not received much attention. A small pilot study of a nurse-monitored Internet discussion board for parents of mentally ill young children concluded that this could be a relatively inexpensive way of providing social support to parents (Scharer, 2005). Participation in online parent support groups allows parents to connect with other parents who are going through a similar experience to themselves (Leonard et al., 2004). Parents join the

groups to share concerns and information (Han & Belcher, 2001) and may feel empowered to make informed choices regarding the ongoing management of their child (Leonard et al., 2004). Sharing problems with parents having similar experiences reduces the feelings of isolation and provides families with various models of coping and caring (Zaidman-Zait & Jamieson, 2004).

An online survey of 114 primary caregivers using over 100 different online parent support groups used stress and coping theory as a guide to measure a number of areas of physical and emotional well-being. Ninety-three percent of the respondents were satisfied with online parent support groups. The author talks about problem-focused coping - "an attempt to alter the source of stress" and emotion-focused coping – "an attempt to reduce or manage the emotional response to perceived stress, as opposed to trying to change the stressor itself." Ninety-nine percent of respondents participated in online support groups to get usable ideas for managing their particular situation – a problem-focused coping strategy; and ninety-four percent participated to help other parents – an emotion-focused coping strategy. The information and support parents receive online can change their perspective on situations and make them more tolerable, providing a sense of relief and gratitude. Most parents in this study recommended that parents with children with special health needs join on online support group as soon as possible (Baum, 2004).

Researchers monitored the Internet use of a randomly chosen sample of families with children with special healthcare needs in geographically dispersed areas of the state of Nebraska, over the period of one year. Participating parents were

provided with suitable hardware, training and ongoing support along with access to the Nebraska Network for Children and Families web site, discussion groups and an email account. Pre- and post- project questionnaires including scales designed to assess empowerment, social support, stress, life satisfaction, and perception of service co-ordinators were completed by both the participating and comparison families. A semi-structured telephone interview was also conducted with 32 of the 40 parents involved in the network after the final questionnaire was received.

This study found highly variable levels of usage which were unrelated to race, education level, income level, previous computer experience or urban-rural location. Differences in pre- and post- test scores of both the project families and the comparison groups showed no significant difference between the groups on measures of empowerment, support, stress, and life satisfaction. These findings were at odds with the qualitative data which were mostly positive. The majority of families indicated that having access to the network and the connections made with other families had the greatest impact on their lives. The authors were unclear as to why this discrepancy between the quantitative and qualitative data exists (Shank, Laible, Murphy-Berman, & Wright, 1999).

Researchers in these studies of parent participation in online parent support groups suggest that this is an area that health professionals should pay more attention to when looking for ways to support parents with children with special health needs. A study of the parents of children with autism and their use of an email group found that the majority of messages specifically asking for help were

posted outside normal business hours when traditional avenues for support are unavailable. The authors speculate that this is indicative that the "traditional biomedical models of practice are insufficient" (Huws, Jones, & Ingledew, 2001).

Equity of access is again an issue and recommendations are made for government intervention to ensure families of lower socio-economic status are not left behind (Baum, 2004). It is generally recommended that further investigation into the most appropriate and effective use of online support groups by parents be undertaken (Baum, 2004; Huws et al., 2001; Leonard et al., 2004; Shank et al., 1999).

2.3 INFORMATION AND SUPPORT NEEDS OF FAMILIES WITH A DEAF CHILD

The consistent evidence that parents of disabled children are not being provided with the timely and crucial information suggests that it has become "somewhat of an intractable problem" (Blackburn & Read, 2005).

The need for parents of deaf children to receive unbiased information, in the face of often strongly held ideological and methodological viewpoints, is often expressed (DesGeorges, 2003; Li et al., 2003; McKellin, 1995). In a survey of seventy-four parents to determine their needs following the diagnosis of a hearing loss in their child, the biggest needs at the time of diagnosis were "contact with other parents, unbiased information, help with their feelings, and getting started with services" (Luterman et al., 1999). Confusing and frequently conflicting claims about communication and educational options can be bewildering and unsettling for families of deaf children (McKellin, 1995). Information that is accurate and reliable enables parents to make informed decisions and take an active role in their

child's management (Bemrose, 2003; DesGeorges, 2003; Luterman et al., 1999). Information empowers parents and provides them with a sense of self-esteem and confidence in their ability to raise a deaf child (Bemrose, 2003; Young, 2003). Enhancing the self-esteem of the parents has been seen as a "powerful intervention" (Luterman et al., 1999) and empowerment of the mother has been found to be the best predictor of literacy achievements in young deaf children (Young, 2003). The process of information gathering undertaken by parents investigating cochlear implantation for their child has been shown to affect both parental coping and the decision-making process (Zaidman-Zait & Jamieson, 2004).

The information needs of families change over time (Harrison & Roush, 2001). Their information needs are different at diagnosis, a few months after diagnosis and at transition phases in their child's life such as entering school (Harrison & Roush, 2001; McKellin, 1995). The need for professional advice and written information tends to rise at these times (Young, Greally, & Nugent, 2003). One survey indicated that parents wanted more information about intervention options with regard to both audiology services and early intervention (Roush, 1998). Another study in 2000, found that the information needs of parents also varied according to the degree of hearing loss of their child (Harrison & Roush, 2001). However, all ranked causes of hearing loss as their main priority at the time of diagnosis and resources about speech and language development a major priority a few months later. Parents expressed the need "to be able to pursue intervention options armed with as much information as possible" (Harrison & Roush, 2001). This study surveyed parents who were receiving a free subscription to a publication of the Alexander Graham Bell Association for the Deaf and Hard of

Hearing, which promotes the auditory-verbal approach and may not represent the needs of parents who have chosen a different methodological approach.

A study of 50 Israeli mothers of young deaf children has similar findings. These mothers wanted more information about "audiology, language development, the general development of the deaf child, and educational opportunities." One mother expressed a common opinion throughout the literature, "All the existing alternatives should be placed before the parent, and the parent should be seen as the one who has the right and the ability to decide what communication and treatment methods are appropriate for her child" (Dromi & Ingber, 1999).

A qualitative study of 27 families of babies diagnosed with a permanent bilateral hearing loss through a newborn screening program, found that parents had no preference regarding the source of the information. The need to revisit certain information to develop full understanding was, however, emphasized (McCracken, Young, Tattersall, Uus, & Bamford, 2004).

In a large study of parents of deaf children carried out in the UK as part of the National Deaf Children's Society (NDCS) Toolkit Development project, one of the main aims was to "assess parent's views about current resources … available to assist them in parenting a deaf child"(Young et al., 2003.) The authors analysed 1290 questionnaires returned by parents and transcripts of 4 focus groups comprising 16 parents which sought to discuss issues in the questionnaire in more detail. While the sample was drawn from families who were NDCS members, it does indicate the opinions of a large number of parents of deaf children.

The NDCS study found that information from professionals and written information rated the highest in the parents' assessment of special resources available. The importance of the Internet rated differently according to whether the parents were hearing or deaf, with 32.5% of deaf parents rating the Internet as important. On the other hand, less than a quarter of hearing parents rated the Internet as an important resource.

Parents in the focus groups expressed difficulties accessing the information they needed and felt this had "impacted significantly on [their] experience of parenting" (Young et al., 2003). Parents expressed anger and resentment that the information they needed was not provided in a systematic and guided fashion. Many spoke of the incidental way they picked up information which was often very important to their parenting of a deaf child. Parents of deaf children were frequently found to be good sources of important information. The report notes that "the experience of poor or hard to access information was an enduring aspect of their parenting experience" (Young et al., 2003). The student feels that this is not dissimilar to the experiences of many families with deaf children in Australia.

2.3.1 The Internet and parents of deaf children

There has been one documented study looking at the Internet and information needs of parents of deaf children. This study evaluates the information that parents are likely to find on the Internet when investigating cochlear implantation for their child. A sample of 31 web sites was evaluated to determine who provided the information about cochlear implants and the relevance of the information to

parents. The information was largely contained on medically-oriented university department or government web sites although manufacturers and consumer self-help groups were also represented. The authors found that much of the information that parents request, particularly on cochlear implants and how they work, was readily available. Other important topics for parents are covered less extensively and, significantly, topics seen as vitally important to parents of deaf children – education, habilitation and communication choices – were very limited or absent altogether. The authors recommend that professionals working with families of deaf children understand the advantages and limitations of the Internet to provide parents with both information and support and to incorporate this new resource into their work with families (Zaidman-Zait & Jamieson, 2004).

In summary, a common concern for parents of deaf children is the difficulty accessing the information they require to ensure the best outcomes for their child and family. The thread through all studies is the call for "more information". The Internet may have the potential to provide parents with timely information that is accessible and meaningful to them.

Chapter 3

AIM AND OBJECTIVES

3.1 AIM

The aim of the present study was to determine the use of the Internet by parents of deaf children seeking information and support within the Australian context.

3.2 RESEARCH OBJECTIVES

The purpose of this study is to more fully understand the reasons that parents of deaf children turn to the Internet and whether any particular variables play a significant role in their Internet use. There are a number of questions that need answering. Do parents of children with different types and degrees of hearing loss have the same frequency of Internet use? Does geographic location impact on their need for either additional information or support? Does cochlear implantation influence Internet use? What information do parents want? Do they find it? What role do online support groups play in providing parents with the information and support they seek from other parents. Clarifying some of these questions will broaden the current knowledge base and may assist in future development of web sites that better meet the needs of Australian families with deaf children.

Chapter 4

METHODOLOGY

The study consisted of two questionnaires – a Parent Survey to evaluate the demographics, Internet experience and information needs of parents of deaf children in Australia (Appendix A), and a pilot survey of parents participating in an online support group for parents of deaf children in Australia (Appendix B). Inclusion and exclusion criteria are outlined in Table 2.

Table 2. Inclusion and exclusion criteria for study respondents

Inclusion criteria
Parent or guardian of a child diagnosed with a permanent hearing loss
Parent and child resident in Australia
Child aged between birth and 21 years
Exclusion criteria
Non-Australian residents
Child does not have a permanent hearing loss
Child over 21 years of age

Both questionnaires were hosted by Questionpro (http://www.questionpro.com). Questionpro provides commercially available online software for surveys. It consists of a wizard interface for creating the survey and tools for recording and analysing the data. Each survey has a unique URL. Data is maintained behind a firewall and can only be accessed by the owner of the survey using a password and

user-id. Data cannot be accessed by others without the permission of the survey owner. All survey data is deleted three days after the account is closed.

The parent questionnaire consisted of an introduction and five sections and took approximately 10 minutes to complete. The introduction explained the aims of the research, information and contact details of the student and the guarantee of anonymity and confidentiality of the survey. It was explained that participation was voluntary and withdrawal from the survey was possible at any point. Checking "Continue" at the end of the introduction was considered consent to participate in the study.

The questionnaire consisted of single answer, multiple choice and open-ended text questions. Radio buttons were used when only one answer was sought and check boxes provided for multiple responses. Some branching was used which allowed for skipping of certain questions based on a previous response. For example, if the respondent marked "No" for "Do you have another deaf child?", the survey skipped the questions about subsequent deaf children.

The Anti-Ballot Box Stuffing (ABBS) feature was not enabled as it was thought that some parents may access the survey from the same computer, such as at a service provider, and this is not possible if ABBS is enabled. This does open the survey up to abuse and multiple surveys by single respondents but reviewing the data and the rate of responses indicates that this was an unlikely event.

The questionnaire was pretested by five parents of deaf children using a hard copy format. It was refined using their comments and suggestions. It has been argued that five tests can reveal 85 percent of the usability problems of online surveys (Burnside, 2000).

4.1 DISTRIBUTING THE SURVEY

The student was interested in responses from parents across Australia with deaf children under 21 years of age. An initial letter was sent to a total of 229 organisations or service providers who offer services to deaf children and their families across Australia. This letter consisted of a brief overview of the research and a request to distribute the URL of the survey to parents using their service. A hard copy of the survey was included. Letters were personalised wherever possible. Details about the survey were subsequently placed on five web sites – Aussie Deaf Kids, Australian Caption Centre, Australian Hearing, Deaf Children Australia and Disability News: Infoxchange Australia.

The Victorian Department of Education and Training, Brisbane Catholic Education Office and the Catholic Education Office for the Diocese of Parramatta requested more detailed information about the study. The required documentation was forwarded to the Victorian Department of Education and Training and Brisbane Catholic Education Office. Documentation was not sent to Catholic Education Office for the Diocese of Parramatta as the late request allowed insufficient time for the distribution of information.

The Victorian Department of Education and Training provided permission for research to be undertaken in their schools. Information was subsequently sent to the nine Regional Directors, fourteen primary school and 10 high school principals and the nine regional itinerant teacher services.

Reminder letters, including a letter to parents, were sent one month after the initial letters to 20 organisations and service providers and 27 early intervention services if no correspondence or phone contact had indicated whether they had distributed the information to parents. Emails were also sent to contacts of the student who work with parents of deaf children, requesting their assistance in distributing information of the study to their networks.

A number of organisations and schools requested flyers or a letter for distribution to parents and these were sent via mail or electronically, as requested.

Some hard copies of the surveys were completed and returned and this data was entered by the student as advised by Questionpro. Date of data entry and the identification number for each completed survey was noted on the hard copy.

The survey was online for a two month period, closing on August 31, 2005.

4.2 ONLINE SUPPORT GROUP SURVEY

A smaller pilot survey was carried out to ascertain the thoughts of parents who participate in online support groups. A convenience sample of parents who were members of two online support groups run by the student was used. Information

about the survey was posted to the two Aussie Deaf Kids online groups – http://groups.yahoo.com/group/phidcoz and http://health.groups.yahoo.com/group/adk_unilateral_loss/ and parents volunteered to complete the online survey.

To ensure the anonymity of respondents, only brief demographic details were requested. The thoughts and opinions of the parents concerning their experience of online support groups were canvassed in an open-text format. The survey took an average of nine minutes to complete.

4.3 ANALYSIS OF DATA

Quantitative data were analysed using frequency distributions and cross-tabulations to assess the relationships between different variables. The Pearson chi-square test was used to identify any statistically significant trends amongst variables. Qualitative data obtained in open-text questions was categorised into broad areas which were then systematically refined.

Chapter 5

RESULTS

5.1 PARENT SURVEY

Information about the survey appeared on five web sites and 229 organisations and service providers were informed of the study. The response rate to the Parent Survey was low. Three hundred and six people viewed the survey. Two hundred and seven started the survey and 166 completed it. Eighty percent of respondents who started the survey completed it, although not all questions were completed by every parent.

5.1.1 The parents

The demographic details of respondents are outlined in Table 3. The majority of respondents were mothers of a deaf child and more than half were aged between 34 and 49 years of age. One parent was of Aboriginal or Torres Strait Islander descent. The vast majority were very comfortable speaking (94.3%) and reading (96.2%) English. Respondents were from across the country with the majority from the three most populous states, New South Wales, Victoria and Queensland, and over half were located in the city.

Parents were equally likely to be employed or unemployed or a homemaker. Almost half the respondents had a university degree and a third reported their highest level of education as high school.

Table 3. Demographic details of respondents

	%	*n*
Relationship to child		
Father	10	15
Mother	89	140
Guardian	1	2
Age (years)		
18-34	29	45
34-49	67	106
50-64	4	6
Employment status		
Employed (full-time/part-time/self-employed	58	91
Unemployed/homemaker/student	42	64
Highest level of education		
High school	36	56
Vocational training	15	24
University degree	49	77
Geographic area		
City	56	87
Regional	31	49
Rural	13	20
State/Territory		
ACT	3	5
NSW	37	59
VIC	25	39
QLD	15	23
NT	<1	1
WA	8	13
SA	9	15
TAS	2	3

5.1.2 The children

Details about the children were also sought and are outlined in Table 4. Most families had only one deaf child and the majority of children had a permanent bilateral hearing loss. The degree of hearing loss was scattered from mild to

profound, which was the most frequent category. Forty-four of the children with a bilateral loss and eleven with a unilateral loss were reported to be in the profound range. The largest percentage of children were aged between 5 and 10 years but all other age ranges, except below 3 months, were represented.

Table 4. Demographic details and hearing status of children

	%	*n*
No. of deaf children in family		
One	82	133
Two	16	26
Three	2	3
Age		
Under 12 months	6	12
12 to 24 months	11	20
2-5 years	26	50
5-10 years	23	43
10-15 years	20	39
15-18 years	9	17
18-21 years	5	10
Type of hearing loss		
Bilateral	90	167
Unilateral	10	18
Method of communication		
Oral	65	123
Manual	7	14
Both	28	53
Child wears hearing aid		
Yes	68	129
No	25	48
Sometimes	7	14
Child has a cochlear implant		
Yes	26	48
No	74	137
Child has another medical condition or disability		
Yes	16	30
No	84	159

Two-thirds of the children use oral communication only and over a quarter communicate using a combination of oral and signing. These figures correlate with the children who wear hearing aids and those who don't. A quarter of the children have a cochlear implant. Sixteen percent of the children had an additional medical condition or disability.

5.1.3 Parents and the Internet

The majority of respondents were very comfortable using the Internet and accessed the Internet from home. (See Table 5) Almost half of the respondents had participated in an online support group or email list for people interested in hearing loss. Fewer had signed up for electronic newsletters dealing with hearing loss.

The most popular way of searching for information is through the use of a search engine. Parents also visit web sites recommended by hearing professionals, other parents of deaf children, family and friends and Australian Hearing's publication for parents – "Choices". A number visit web sites that specialise in hearing loss.

There is a wide variation in the frequency with which parents access the Internet for information about deafness with some reporting daily access and others every few months or less. Thirty-one percent access the Internet several times a month to search for information about deafness.

Two-thirds of respondents visit two to five web sites to find the information they require. Some parents visit only one site while some visited more than 20 web sites per visit. Less than 20% always use Australian web sites although almost half visit

Australian web sites most of the time. More than half the parents find the information they are seeking most of the time, although a third report that they only sometimes find the information they need.

Table 5. Internet use of respondents

	%	*n*		%	*n*
Comfort using Internet			*Finding information*		
Very comfortable	67	109	Search engine	87	135
Somewhat comfortable	23	38	Hearing loss web site	44	68
Access the Internet			Web sites in "Choices"	5	8
Home	89	146	Hearing professional	16	25
Work	9	14	Friend/family	11	18
Frequency of use for deafness topics			Parents of deaf children	31	49
Every day	12	20	*Influence on decision-making*		
Several times a week	17	27	Major influence	18	29
Several times a month	31	50	Minor influence	58	94
Every few months	21	34	Other	24	38
Less often	17	28	*Talked to doctor/hearing professional*		
Number of web sites per visit			Yes	52	82
One	4	6	No	43	69
Two-three	35	57	*Participated in online support group*		
Four-five	29	46	Yes	49	78
Six-ten	17	27	No	51	80
Eleven -20	4	6	*Receive electronic newsletter*		
More than 20	3	5	Yes	30	47
			No	70	112

Half of the respondents had spoken to their doctor or other hearing professional about the information they had found on the Internet. Half felt the professional was somewhat interested in the information the family had found in their Internet searches. Twenty five percent felt they were very interested in the information.

Sixty percent of respondents report that the information they find on the Internet has a minor influence on their decision-making regarding their deaf child. For 18%

of respondents, the information on the Internet has a major influence on their decision-making.

Cross-tabulations and chi-square analysis indicates that the pattern of Internet use, both for information-seeking and online support is unrelated to the age of the parent, the age of their child, where they live or their employment status. Their use of the Internet is also unrelated to the type of hearing loss of their child (i.e. bilateral or unilateral), if their child has a cochlear implant or an additional disability or medical condition, or the method of communication used by the child.

Education level, however, does influence the level of Internet use. Parents with a university education are more frequent users of the Internet for information seeking ($p<0.05$) and the information they find has a major influence on decisions they make about the management of their child's hearing loss ($p<0.05$). They are also more likely to participate in online support groups ($p<0.05$).

5.1.4 What information are parents searching for on the Internet?

Parents get their information about their child's hearing loss and other related issues from a variety of sources with Australian Hearing and the Internet the most frequent sources. Half of the parents didn't use the Internet at the time of diagnosis. Although the reason for this was not investigated, a number of parents indicated they did not have a computer or access to the Internet at the time of diagnosis of their child's hearing loss. The majority of parents who did use the Internet at the time of diagnosis were looking for information about hearing loss. They also searched for information about hearing aids, communication options,

cochlear implants and early intervention services. Half searched for information about parent support groups.

At the time of the survey, the two most common topics searched for on the Internet by parents were parent support groups and educational options as outlined in Table 6. This was consistent irrespective of the age of the child. Information about hearing loss, hearing aids, cochlear implants and other assistive listening devices continue to be popular topics for Internet information-seeking by parents.

Table 6. Information parents search for on the Internet

	%	*n*
Parent support groups	55	85
Educational options	54	84
Hearing loss	40	62
Organisations & societies	39	60
Hearing aids	35	55
Communication options	30	46
Cochlear implants	28	43
Early intervention	17	27
Mental health	8	13
Alternative treatment/management	6	10

Around ninety percent of respondents have never visited the Australian Government's health information gateway – Health*Insite* – or Medline Plus. Almost fifty percent of parents have never visited the web sites of a number of the peak bodies and organisations which provide services to Australians with a hearing loss. Australian Hearing and two web sites which focus on deaf children (Aussie Deaf Kids and Deaf Children Australia) were the most frequently visited of Australian web sites.

5.1.5 What would parents like to find on the Internet?

Eighty-two parents responded to the final open-text question which asked parents what information they would like to see included on Australian web sites about deafness and related topics. Common themes are summarised in Table 7.

Table 7. What parents would like to find on the Internet - common themes.

Early intervention	*Education*
Evidence-based outcomes	Evidence-based options
Comprehensive information regarding different methodologies	Guidelines for parents, teachers and classmates
Communication	Further education options
Unbiased information backed by research findings	*Mental health*
Speech/language	Behaviour
Outcomes and expectations	Self-esteem
Tips and techniques	Socialisation
Technology	*The future*
Updates on new developments	Careers
Future trends	Employment options
Stories	*Funding and financial assistance*
Stories about children	General advice and guidelines
Successful Deaf/deaf adults	*Research*
Parent support	Current research updates
Parent groups	*Unilateral hearing loss*
Continuing parent education	Resources for parents and teachers

Common to many areas is the need for unbiased information, which is evidence-based, in order for parents to make informed choices. Parents want to find objective information about their options with regards to early intervention, education, communication and technology. They want information about current research and developments in the area of assistive technology. Parents enjoy the stories of other families and Deaf adults. Some ask for success stories while others would like to know the ups and downs of having a deaf child.

Parent support and information was another strong theme. Information about parent support groups and parent mentors was mentioned as well as information for continuing education for parents such as Auslan classes and parent workshops and seminars.

A number of parents with older children would like information about what happens after school – careers advice, employment options and hearing support at universities and TAFE.

Mental health issues were another area of interest, particularly behaviour issues.

In summary, respondents to this parent survey were likely to be well-educated, English-speaking mothers who are very comfortable using the Internet. They are looking for a wide variety of information about hearing loss and other issues important in the lives of families with a deaf child. They want more information available on the Internet and the information should be unbiased and evidence-based.

5.2 ONLINE SUPPORT GROUP SURVEY

This survey of a small sample of parents who participate in the online support group, Aussie Deaf Kids, was intended to provide a snapshot of the Australian experience of parents of deaf children who participate in online support groups. Aussie Deaf Kids is for members only and is operated by the student. Members are

parents of deaf children only and, with a couple of exceptions, live in Australia. The demographic details of the respondents are detailed in Table 8.

This survey was largely qualitative – addressing the opinions of parents about online support groups. Most parents belong to only one online support group associated with hearing loss and a quarter had been participating in online support groups for three or more years. Half of them found the group by "surfing the net". Most receive the messages via email and prefer this method to a chat format.

Table 8. Demographic details of online support group respondents

	%	*n*
Relationship to deaf child		
Father	5	1
Mother	95	19
Age		
18-34	40	8
35-49	60	12
Geographic area		
City	55	11
Regional	35	7
Rural	10	2
Level of education		
High school	20	4
Vocational training	15	3
University degree	65	13

Forty-five percent of the parents participated daily in an online group either reading and/or sending messages. In fact, ninety percent participated at least once a week. All of these parents would recommend online support groups to other parents with a deaf child. Seventy percent felt that parents should join an online group as soon as possible after the diagnosis of their child's hearing loss.

Two-thirds of the parents have met face-to-face after meeting online. One parent felt this added to the experience of participating in an online group – "You put a human face to the stories…".

A summary of what parents like about online support groups is provided in Table 9. Parents like being in an environment where everyone is on a similar journey and realising that they were not alone. The support is available when you need it and one parent felt that "discussing things with other parents is the best way to help share the grief and move forward."

Table 9. Summary of reasons parents like online support groups

Support - "…support is genuine…"
Information - "There is always someone who knows the answer to your question!"
Understanding - "It is nice to know there are other people going through the same situation…"
Helping others - "I feel good helping others with their questions."
Convenience - "I think it is a wonderful idea as you don't need to leave the house so you can participate at any time."

Online support groups were seen as an important source of information for parents. The information is described as parent-friendly and based on real-life experience. Parents also enjoy being able to support other parents and answer their

questions and queries. A number of parents commented on the non-judgmental environment of online support groups. While conflicting ideas do emerge and some parents can hold very strong views, they felt that a healthy discussion was important as long as it wasn't abusive.

The convenience of online groups is important – the ability to participate at a time and place that is convenient for families. Parents like to "lurk" and feel there is no pressure to be active participants.

Although four parents wrote that there was "nothing" they didn't like about online support groups, there were areas of concern for others. The sentiments expressed by parents are similar to those expressed elsewhere including the anonymity of members, the difficulty of interpreting email language and the potential for messages to be misinterpreted. Parents who dominate discussions or hold very strong views are "tiring." The difficulties of an evolving group were also discussed. The irritation of the same questions being asked repeatedly was acknowledged although a measure of understanding and tolerance was indicated. The difficulties experienced by new members to feel part of the group, was another area of concern.

One parent summed up the thoughts of many:-
"I find the online group extremely helpful. I don't feel so alone when dealing with the various issues that come up when you have a child with a hearing loss. I also enjoy being able to pass on advice and ideas to other parents who are new to the journey and helping share my knowledge to help make their journey easier."

Chapter 6

DISCUSSION

The purpose of this study was to examine the experience and expectations of parents of deaf children living in Australia who use the Internet for information and support. The study was aimed at parents who currently use the Internet to search for further information about hearing loss and their perceptions of participating in an online support group.

Some mention should be made of the survey methodology. The anonymous nature of the survey makes it impossible to verify whether the parents meet the inclusion criteria. However, all respondents indicated residence in an Australian State or Territory, children were all aged under 21 years and respondents indicated that they were either the mother, father or guardian of a deaf child.

While Internet surveys have been shown to be comparable to traditional surveys in terms of validity and reliability of the data, generalisability to the population under investigation is an important consideration (Eysenbach & Wyatt, 2002). Researchers have suggested that online surveys have the potential for a number of biases as a result of coverage error, sampling error, measurement error and non-response error (Umbach, 2004).

As the surveys targetted parents who use the Internet, coverage error is not a concern in these parent populations (Schonlau, Fricker, & Elliott, 2001). Online surveys also minimise the potential measurement error as data is automatically

entered by the respondent. However, the survey may appear different in various Web browsers or operating systems which can introduce the potential for measurement error (Umbach, 2004). A number of design principles for online surveys are recommended to reduce this potential for measurement bias (Umbach, 2004) and they were utilised in these surveys wherever practicable. These include ensuring the survey is easy to navigate and read; avoiding too much colour; using a format that is comparable to traditional paper questionnaires; limiting line length; dividing surveys into sections and allowing scrolling from question to question.

Selection bias, however, is possible. Distribution of the survey details was dependent on the organisations or service providers notified, a total of 229 across the country, and it is not possible to know how many informed parents of the study. One service provider mentioned to the student that they did not distribute the information as most of their parents did not have Internet access. Selection bias is also an issue as parents volunteered to complete the survey and parents who select themselves for a study may not be the same as the population as a whole (Beaglehole, Bonita, & Kjellstrom, 1993). Online surveys increase the likelihood of non-response bias which is a concern in this survey. There is no way of knowing how parents who failed to participate in the survey differ from those who completed the survey.

A further issue for selection bias is the student's involvement with Aussie Deaf Kids – an online support group and web site for families of deaf children in Australia. This may well inflate certain responses, particularly the numbers of

parents who have participated in an online support group. It is impossible to know from the survey results how many of the parents who answered "Yes" to this particular question, are members of an Aussie Deaf Kids group.

The limitations of the online support group survey also need to be acknowledged. The sample of twenty parents is small. The group was started by the student and this may have affected how parents responded to the survey. However, their completion of the survey was voluntary and anonymous. Non-response bias is a particular concern here and it cannot be said that the responses of the participating parents is representative of the online group parents or the population of parents of deaf children as a whole.

In retrospect, a mixed-mode response may have been a better option - providing participants with a choice about how to complete the survey – either online or hard copy. Mixed-mode response is encouraged by some authors to improve response rates and Umbach (2004) found no significant differences between the two modes in one study. This option was not mentioned in the letters or introduction to the survey although some service providers did supply parents with hard copies and fourteen hard copies were returned. However, as parents who currently use the Internet were being surveyed, it was decided that an online survey was the most cost effective method of administration.

There is a discrepancy in the data which also warrants highlighting. The survey targetted parents who currently use the Internet for information or support. However, in the question which asked parents where they get information about

their child's hearing loss and related topics, only 69% reported using the Internet. The student is unable to explain this discrepancy.

This study has a major limitation - the hearing status of parents was not evaluated. This was a serious oversight and could have provided some valuable information regarding the needs of Deaf parents and their use of the Internet. The National Deaf Children's Society (NDCS) Toolkit Development project (Young et al., 2003) found more deaf parents than hearing parents rated the Internet as an important resource and comparable data for Australia should be sought.

The study found that parents' use of the Internet was unrelated to the age of the parent, the age of their child, where they live or their employment status. Their use of the Internet is also unrelated to the type of hearing loss of their child (i.e. bilateral or unilateral), if their child has a cochlear implant or an additional disability or medical condition or the method of communication used by the child.

Education level, however, does influence the level of Internet use. In Australia, people with a university education are more than two and a half times more likely to have Internet access from home (Curtin, 2001). Parents in this study, with a university education, are more frequent users of the Internet for information-seeking and the information they find has a major influence on decisions they make about the management of their child's hearing loss. They are also more likely to participate in online support groups.

This raises the issue of inequality of access – the so-called 'digital-divide'. Respondents to this survey were almost exclusively comfortable speaking and reading English and only one parent of Aboriginal or Torres Strait Islander descent completed the survey. A study of ethnic minority families with a severely disabled child in the UK in 1999, found these families and children to have greater reported unmet needs, including information and support, than their white counterparts (Chamba, Ahmad, Hirst, Lawton, & Beresford, 1999). While the ethnic backgrounds are different, one would suspect that the picture would be similar in Australia. *Curtin* (2001) has discussed how we have little idea about the Internet use of ethnic minorities in Australia and how this population is underserved with little multi-language content available on Australian web sites. The responsibility of Government and policymakers to ensure equity of access across the ethnic and socio-economic divides has been discussed by various authors (Baum, 2004; Blackburn & Read, 2005). Accessible information and knowledge is potentially empowering (Mitchell & Sloper, 2002) and reduces feelings of distress, confusion and hopelessness (Huws et al., 2001). In addition, empowerment of the parent influences parental coping and is a predictor of outcomes for the disabled child (Baum, 2004; Young, 2003; Zaidman-Zait & Jamieson, 2004). If disadvantaged and ethnic minority families are to make informed decisions about the management of their child's hearing loss, they deserve equity of access to all information – professional, written and online. It has been said that failure of an individual to develop competencies is a failure of the systems which provide individuals with the means of developing competencies (Mitchell & Sloper, 2002).

This survey confirms that parents predominantly use a search engine to find the information they need (*Excerpt of the 8th HON's survey of health and medical internet users*, 2002). Search engines, however, are not directing parents to so-called 'gateway' web sites such as Health*Insite*, the Australian Government initiative to provide Australians with a "gateway to reliable health information" (*HealthInsite,* 2005). Ninety-two percent of the parents in this survey – that is, parents who use the Internet to search for information – had never visited Health*Insite* to look for information about hearing loss. Furthermore, eighty-nine percent had never visited Medline Plus. These gateway sites may be too generalist for the needs of parents, but the reason why so few are visiting these sites warrants further investigation.

This study did not look at how or if parents validate the information they find on the Internet. However, a number of parents commented on the quality of information in the open-text questions. Parents asked for information that is evidence-based and referenced to journal articles. One parent wrote, *"I do not visit web sites because they do not provide sophisticated information supported by the details of the research by which it was established."* While this view is probably extreme, Zaidman-Zait and Jamieson (2004) noted in their article on cochlear implantation information on the Internet that little attempt was made to direct parents to research articles in the public domain.

Parents do need to be directed to quality information and it has been suggested in many quarters that this is the role of the health professional (Mitchell & Sloper, 2002; Zaidman-Zait & Jamieson, 2004). In this study, half the parents had talked to their doctor or hearing professional about information they had found on the

Internet. It is encouraging to find that over eighty percent of these professionals were very or somewhat interested in what the parents had found. Hearing professionals need to support and guide parents through their information-seeking and decision-making process and move away from being the gatekeepers of knowledge to advisors and partners in the process (Yellowlees & Brooks, 1999).

A number of parents wrote about their need for unbiased information to make informed choices and their wish for the information to be evidence-based. The frustration of parents about the nature of the information they receive was reflected in the comment of one parent, *"Some unbiased (yeah I know, I seek the impossible) info (sic)…".*

The information available to parents on Australian web sites is limited, if not rudimentary. An overview of the web sites of the principal Australia-wide organisations and service providers indicates that the main information provided is about hearing loss *per se*. This survey indicates that 'hearing loss' is an ongoing topic of need for parents. However, as noted by *Zaidman-Zait and Jamieson* (2004), other topics such as education and mental health, areas of major concern for families with a deaf child, are mostly absent from these Australian web sites.

There are a number of excellent web sites in the US and United Kingdom for families of deaf children. However, their hearing service delivery and education systems are very different to the Australian experience and the information may be either irrelevant or not applicable to Australian parents. The intellectual philanthropy of the US is evidenced in their organisational and educational web

sites dealing with deafness, which have enormous amounts of good quality information available on the every day management of a child with a hearing loss.

This willingness to share knowledge and ideas with parents is not evidenced in the Australian context. In the light of the fact that parents are asking for evidence-based information about communication, education and outcomes, the proposition for public accessibility to good quality scholarly journals, may have considerable appeal for parents (Willinsky, 2003). Alternatively, the summary of evidence-based information found in the "Abstract" of scholarly journals may provide the solution to bridging the information gap between parents and professionals (Jadad, 1999).

Zaidman-Zait and Jamieson (2004) talk about Willinsky's idea of making scholarly research available to everyone. While everyone is entitled to the information they need in a form that they can understand, it seems unethical that parents should not be exposed to the same information that health professionals and educators have access to when promoting different communication, education and assistive technology choices. It has been shown that motivated parents can read quite sophisticated information in an area of interest. Parents of deaf children are on a very steep learning curve at the time of diagnosis but many reach a complex level of understanding about hearing loss very quickly and deserve to have the same access to evidence-based information when deciding on issues that are "formidable and life altering" (Kurtzer-White & Luterman, 2003), as the professionals guiding and supporting them.

The survey also highlights that parents of older children continue to use the Internet for information-seeking. Parents of disabled children have indicated the need for targetted information at key milestone periods such as diagnosis, starting school and the transition from school (Mitchell & Sloper, 2002). Parents in this survey wanted more information on careers advice, employment options and support available for their children in the transition from school to work or further study. While parents attend early intervention services, their information and support needs are usually well met. However, increasing numbers of deaf children are now being mainstreamed and may be the only deaf child in the school. Parents whose child is mainstreamed may have little contact with other parents and infrequent contact with hearing professionals. However, their need for information continues and they may well be turning to the Internet for information on issues such as education, mental health and careers as a result of this reduced contact with their previous support and information sources.

The survey of twenty parents participating in an online support group has confirmed the findings of other studies evaluating the use of online support groups for parents with children with special healthcare needs (Baum, 2004; Huws et al., 2001; Scharer, 2005; Shank et al., 1999). Parents appreciate the support and information provided by parents who have walked the road before them. This survey confirms Baum's (2004) results that the majority of parents would recommend other parents join an online support group as soon as possible after the diagnosis of their baby's hearing loss. This is worth noting in light of the fact that seventy percent of the respondents learnt about online support groups through surfing the Net or from other parents. There appears to be a reluctance

amongst hearing professionals to recommend this source of support to parents despite their potential to provide support, information and reduce feelings of isolation and frustration. Zaidman-Zait and Jamieson (2004) have discussed that the community-building potential of online groups should not be overlooked, particularly for families in rural areas.

Families living in cities also enjoy the support and information provided by online support groups. In the Online Support Group Survey, fifty-five percent of parents lived in the city which may indicate that they are not immune to feeling of isolation and need for contact with other parents. Professionals working with families with a deaf child should encourage parents to join an online support group that meets their particular needs. Professionals should not assume that parents connected to services and organisations would not benefit from participation in an online support group. Professionals should become informed about well-managed online support groups which meet the needs of their particular client base. Failure to do so, may well deprive families of the benefits of sharing experiences, offloading frustrations and obtaining specific information about the management of their child's hearing loss.

It must be acknowledged that not all parents are interested in online support groups. However, parents and professionals alike need to find ways of facilitating online support for families who may be interested in participating, but cannot, due to economic, language or other barriers.

The Internet may also provide a more equitable and accessible way for families to participate in service development. There is an increasing emphasis on parent involvement in decision-making with regards to services. The difficulties imposed by traditional face-to-face meetings for families such as travel time and cost, child care and time allocation can largely be eliminated by email communication. Families from a wide geographic area can contribute to committees at a time and location that is convenient to them. This may be an attractive prospect for rural families wishing to advocate for services in their area.

This community-building potential of online support groups may also have political implications. The online parents who are disaffected by service provision may well feel empowered to join together in order to affect political change. Although the political implications of online support groups have yet to be considered or studied, the Internet does play an increasingly important role in communication between politicians and their constituents (Shank et al., 1999) and the prospect of online families advocating for change is an intriguing possibility.

The Internet itself may provide the conduit for collaboration between parents and professionals in creating and evaluating Internet resources that are "relevant, valid, engaging, and ready to apply" (Jadad, 1999).

Chapter 7

CONCLUSION

Prior to this study, there was little published information about parents of deaf children and their use of the Internet to find information and support. This dissertation provides a solid foundation about these parents, how they find information and their particular information and support needs.

Parents of deaf children in Australia are using the Internet searching for both information and support to assist them in raising a deaf child. Internet use is unrelated to the age of the parent or the child. In fact, parents appear to continue to search for information throughout the life of their deaf child. Parents need information and support irrespective of the type of hearing loss of the child, the means of assistive technology or method of communication used by the child. The Internet, however, remains the domain of parents who are competent in English.

Parents report the need for unbiased information that is evidence-based, particularly with regard to communication options, early intervention and education. Some frustration at the continual need to request unbiased information is evident in a number of responses.

Respondents to the Online Group Survey were enthusiastic proponents for this form of parent support. The parent-friendly information is a major feature of their interest. The support assists them to deal with their grief and move on and their

ability to provide support to other parents is a source of satisfaction. All parents would recommend online support groups to other families.

Young adults who are becoming parents today have probably been using computers, the Internet, chat rooms and email for a large percentage of their lives. They are used to accessing information instantly – when they want it. It is likely that the importance of online information, support and communication will increase over time. Service providers and hearing professionals will need to understand this changing dynamic and adapt their web sites and information provision accordingly.

7.1 IMPLICATIONS FOR FURTHER RESEARCH

This study indicates a number of areas that may warrant further investigation.

The experiences of parents who join online support groups but unsubscribe has not been investigated. A better understanding of their reasons for unsubscribing and the benefits or risks their participation had on them, would contribute to the knowledge of the efficacy of these groups for parents.

Mitchell and Sloper (2002) found that parents favoured a guide to be their key reference about where to find resources and information. The Internet has the unique potential to provide this guide. A gateway web site for deafness in children in Australia which can provide parents with current evidence-based information on a broad range of subjects and issues and in a format that is accessible and user-friendly, has the potential to solve many of the unmet information needs of

parents. A gateway web site may provide an online community where parents can access information, support and communicate with each other or experts in a safe, informed environment at a time and place that is convenient to them. This would be a considerable undertaking requiring unprecedented cooperation between service providers, the Deaf community and parents.

Australian Hearing is also uniquely placed in providing access to online information to parents, as almost every child from diagnosis to 21 years of age with a permanent hearing loss is seen in one of their centres. A pilot study of an office-based Internet patient education system in a community-based family practice provided patients with access to the Internet in an unused examination room in the practice. A medical student was available to help them and searching was limited to a Web page directory created for the study. The authors reported that even patients with limited computer and Internet knowledge could find information and reported improved patient satisfaction. Ninety-two percent of the participants wanted to use the Internet again (Helwig, Lovelle, Guse, & Gottlieb, 1999). Given that Australian Hearing has approximately eighty offices cross the country with broadband connections, a similar program for the provision of Internet access to parents on hearing-related information could assist in reducing the digital-divide.

7.2 CONCLUSION

This study provides a foundation regarding the Internet use of parents of deaf children from an Australian perspective. The information gathered through the surveys indicate the direction that parents of deaf children would like service

providers and hearing professionals to take when developing Internet resources for parents of deaf children in Australia.

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APPENDIX A

Parent Survey

Dear Parent,

You are invited to participate in a survey on the use of the Internet by parents of deaf and hearing impaired children in Australia. As the parent or guardian of a deaf/hearing impaired child (aged 0-21 years) living in Australia, we would like to know more about how YOU use the Internet for information about hearing loss and related topics. This information may assist organisations and service providers within Australia to provide the information that parents need and want on the Internet. It will take approximately 10 minutes to complete the questionnaire and there is plenty of room for additional comments and ideas at the end.

Your participation in this study is completely voluntary. Your survey responses will be anonymous and strictly confidential. If you feel uncomfortable answering any questions, you can withdraw from the survey at any point.

This study, to determine the use of the Internet by parents of deaf and hearing impaired children in Australia for information and support, is part of a dissertation for my Masters in eHealthcare through the University of Queensland.

If you have any questions at any time about the survey or the procedures, you may contact Ann Porter at 02 9960 2401 or by email at portabl@bigpond.net.au.

Thank you for your support and time. Please start the survey now by clicking on the 'Continue' button below.

I. Sources of information about your child's hearing loss and related topics

Who is the main person in your family responsible for finding information about hearing loss?

- ○ Myself
- ○ Spouse or partner

Where do you get information about your child's hearing loss and related information?
Please tick all that apply.

- ☐ Health care provider
- ☐ Australian Hearing
- ☐ Early intervention service
- ☐ Teacher of the deaf
- ☐ Cochlear implant centre
- ☐ Internet/web sites
- ☐ Books
- ☐ Family and friends
- ☐ Word of mouth
- ☐ Media eg. television and newspapers
- ☐ Other

II. Information about your use of the Internet to find information about deafness and related topics

How comfortable are you using the Internet?

- ○ Very comfortable
- ○ Somewhat comfortable
- ○ Neither comfortable nor uncomfortable
- ○ Somewhat uncomfortable
- ○ Very uncomfortable

From where do you most often access the Internet?

- ○ Home
- ○ Work
- ○ Some place else
- ○ Don't know

How often do you use the Internet to find information about deafness and related topics?

- ○ Every day
- ○ Several times a week
- ○ Several times a month
- ○ Every few months
- ○ Less often
- ○ Don't know

When you go online to look for information about deafness and related topics, how often are you able to find the information you are looking for?

- ○ Always
- ○ Most of the time
- ○ Only sometimes
- ○ Hardly ever
- ○ Never
- ○ Don't know

About how many different web sites do you usually visit or browse when looking for information about hearing loss?

- ○ One
- ○ Two or three
- ○ Four or five
- ○ Six to ten
- ○ 11 to 20
- ○ More than 20
- ○ Don't know

How do you find or search for hearing-related web sites?
Please tick all that apply.

- ☐ Use a search engine such as Google or Yahoo
- ☐ Visit a web site that specialises in hearing loss
- ☐ Visit web sites recommended by "Choices"
- ☐ Visit web sites recommended by doctor or hearing professional
- ☐ Visit web sites recommended by a friend or family member
- ☐ Visit web sites recommended by parents of deaf/hearing impaired children
- ☐ Don't know
- ☐ Other

When your child was FIRST DIAGNOSED with a hearing loss, what topics of information did you look for on the Internet?
Please tick all that apply.

- ☐ Didn't use the Internet for information at time of diagnosis
- ☐ Hearing loss
- ☐ Hearing aids
- ☐ Cochlear implants
- ☐ Assistive listening devices
- ☐ Communication modes
- ☐ Early intervention options
- ☐ Educational options
- ☐ Alternative treatment/management options
- ☐ Organisations and societies
- ☐ Parent support groups
- ☐ Mental health and deafness
- ☐ Other

What topics of information do you look for NOW on the Internet?
Please tick all that apply.

- ☐ Hearing loss
- ☐ Hearing aids
- ☐ Cochlear implants
- ☐ Assistive listening devices
- ☐ Communication modes
- ☐ Early intervention options
- ☐ Educational options
- ☐ Alternative treatment/management options
- ☐ Organisations and societies
- ☐ Parent support groups
- ☐ Mental health and deafness
- ☐ Other

When you look for online information on hearing loss are the web sites you visit Australian?

- ○ Always
- ○ Most of the time
- ○ Only sometimes
- ○ Hardly ever
- ○ Never
- ○ Don't know

In general, does the information you find on the Internet influence the decisions you make about your deaf/hearing impaired child?

- ○ Major influence
- ○ Minor influence
- ○ No influence at all
- ○ Don't know

Have you talked to a doctor or other hearing professional about information you have found on the Internet?

- ○ Talked to the doctor or other hearing professional
- ○ Didn't talk to the doctor or other hearing professional
- ○ Don't know

If you talked to the doctor or other hearing professional, how interested were they in hearing about the information you found on the Internet?

- ○ Very interested
- ○ Somewhat interested
- ○ Not too interested
- ○ Not at all interested
- ○ Don't know
- ○ Not applicable

Have you ever participated in an online support group or email list for people interested in hearing loss?

- ○ Yes
- ○ No
- ○ Don't know

Have you ever signed up for an electronic newsletter that emails the latest news about hearing?

- ○ Yes
- ○ No
- ○ Don't know

III. Information about your deaf/hearing impaired child(ren)

The following questions are about your first child with a hearing loss

Age

-- Select --

Age at diagnosis

-- Select --

Type of hearing loss

- ○ Bilateral
- ○ Unilateral

Degree of hearing loss

Method of communication

- ○ Oral
- ○ Manual
- ○ Both

Does Child 1 wear a hearing aid(s)?

- ○ Yes
- ○ No
- ○ Sometimes

Does Child 1 have a cochlear implant?

- ○ Yes
- ○ No

Does Child 1 have another medical condition or disability?

- ○ Yes
- ○ No

Do you have another child with a hearing loss?

- ○ Yes
- ○ No

The following questions are about your second child with a hearing loss.

Age

-- Select --

Age at diagnosis

-- Select --

Type of hearing loss

- Bilateral
- Unilateral

Degree of hearing loss

Method of communication

- Oral
- Manual
- Both

Does Child 2 wear a hearing aid(s)

- Yes
- No
- Sometimes

Does Child 2 have a cochlear implant?

- Yes
- No

Does Child 2 have another medical condition or disability?

- Yes
- No

Do you have a third child with a hearing loss?

- Yes
- No

The following information is about your third child with a hearing loss.

Age

-- Select --

Age at diagnosis

-- Select --

Type of hearing loss

- Bilateral
- Unilateral

Degree of hearing loss

Method of communication

- Oral
- Manual
- Both

Does Child 3 wear a hearing aid(s)

- Yes
- No
- Sometimes

Does Child 3 have a cochlear implant?

- Yes
- No

Does Child 3 have another medical condition or disability

- Yes
- No

IV. Information about yourself

What is your relationship to your deaf/hearing impaired child(ren)?

- ○ Father
- ○ Mother
- ○ Guardian

What is your age?

- ○ Under 18
- ○ 18-34
- ○ 35-49
- ○ 50-64
- ○ 65 or older

Which State of Territory do you live in?

-- Select --

What location would BEST describe where you live?

- ○ City
- ○ Regional
- ○ Rural

What is your HIGHEST level of education?

- ○ High school
- ○ Vocational training
- ○ Undergraduate degree
- ○ Postgraduate qualification

Are you

- ○ Employed (either full time/part-time/self-employed)
- ○ Unemployed/homemaker/student

How comfortable are you SPEAKING English?

- ○ Very comfortable
- ○ Somewhat comfortable
- ○ Neither comfortable nor uncomfortable
- ○ Somewhat uncomfortable
- ○ Very uncomfortable

How comfortable are you READING English?

- ○ Very comfortable
- ○ Somewhat comfortable
- ○ Neither comfortable nor uncomfortable
- ○ Somewhat uncomfortable
- ○ Very uncomfortable

Are you of Aboriginal or Torres Strait Islander descent?

- ○ Yes
- ○ No

V. Web sites and hearing loss

Please indicate which of these web sites you have visited in the past and how often you have visited them.

	Never	Once	2-5	5+
HealthInsite	○	○	○	○
Australian Association of the Deaf	○	○	○	○
Australian Caption Centre	○	○	○	○
Australian Communication Exchange	○	○	○	○
Deaf Children Australia	○	○	○	○
Aussie Deaf Kids	○	○	○	○
Royal Institute for Deaf and Blind Children	○	○	○	○
Cochlear Ltd	○	○	○	○
Deafness Resources Australia	○	○	○	○
Australian Hearing	○	○	○	○
Medline Plus	○	○	○	○
Deafness Forum	○	○	○	○

What information would you like to see included in Australian web sites about deafness and related topics?

Please contact portabl@bigpond.net.au if you have any questions regarding this survey.

APPENDIX B

Online Support Group Survey

Hello Aussie Deaf Kid parents,
You are invited to participate in a follow up survey to understand more fully the role online support groups play in the lives of parents of deaf and hearing impaired children in Australia. Only parents who participate in the Aussie Deaf Kids online support groups will be asked to participate.

Your participation in this study is completely voluntary. However, if you feel uncomfortable answering any questions, you can withdraw from the survey at any point.

Your survey responses will be stricly confidential and data from this research will be reported only in the aggregate. Your information will be coded and will remain confidential. Quotes from the survey may be used when reporting on the data but these will remain anonymous and unidentifiable.

If you have questions at any time about the survey or the procedures, you may contact Ann Porter at 02 9960 2401 or by email at the email address specified below.

Thank you once again for your time and support. Please start with the survey now by clicking on the **Continue** button below.

What is your relationship to your deaf/hearing impaired child(ren)?

- ○ Father
- ○ Mother
- ○ Carer/guardian

What is your age?

- ○ Under 18
- ○ 18-34
- ○ 35-49
- ○ 50-64
- ○ 65 or older

What location would BEST describe where you live?

- ○ City
- ○ Regional
- ○ Rural

What is your highest level of education?

- ○ High school
- ○ Vocational training
- ○ Undergraduate degree
- ○ Postgraduate degree

How many online parent support groups that deal with hearing loss do you belong to?(Names of groups may be included.)

How long have you been using online parent support groups?

How did you learn about online parent support groups?

How long after your child was diagnosed with a hearing loss did you join an online parent support group?

How do you read the messages from the online parent support groups?

- [ ] Email
- [ ] Daily digest
- [ ] Visit the web site
- [ ] Other

Which form of online parent support do you prefer?

- [ ] Email
- [ ] Chat
- [ ] Either email or chat
- [ ] No preference
- [ ] Other

How often do you participate in an online parent support group (reading and/or sending messages)?

- ○ Daily
- ○ 2-3 times a week
- ○ Once a week
- ○ Other

Have you met any parents face-to-face after meeting them in an online parent support group?

- ○ Yes
- ○ No

Would you recommend online parent support groups to other parents with a deaf or hearing impaired child?

- ○ Yes
- ○ No
- ○ Unsure

How soon after diagnosis would you recommend parents join an online parent support group?

What do you like about online parent support groups?

What don't you like about online parent support groups?

Do you have any other comments about online parent support groups that you would like to add?

Please contact portabl@bigpond.net.au if you have any questions regarding this survey.